

Testimony by Bob Sedlmeyer
Subcommittee on Criminal Justice, Drug Policy and Human Resources
Hearing on Federal Health Programs and Those Who Cannot Care for Themselves: What Are
Their Rights and Our Responsibilities
April 19, 2005

Good afternoon. My name is Bob Sedlmeyer. I appreciate this opportunity to share my experiences of caring for an incapacitated child. I am an Associate Professor of Computer Science at Indiana University Purdue University Fort Wayne. I am a consultant to Raytheon Net Centric Systems. I am a lay minister for the LifeTeen youth program at St. Vincent de Paul Catholic Church. I am son to Bob and Mary Lou and husband to Cheryl. I speak to you today, however, as the father of Pam, Rob, Valerie, Vanessa, and Tim.

Let me begin by telling you about my daughter, Valerie. Valerie is 19 years old. Her name comes from the Latin word for "strength," but if she were by my side today you would think that she is one of the weakest persons you have ever seen. Valerie suffered a congenital defect of her circulatory system called an AV-malformation. It is a condition that results in a knot of blood vessels instead of an orderly array of arteries and veins. Her knot was formed deep inside her brain. From the moment she was born her brain was starved for oxygen. A series of experimental surgeries saved her life but could not prevent the extensive and permanent damage to her brain.

Valerie is not unlike Terri Schiavo. Spinal fluid fills the areas where her brain has withered and died. Some would say that she is in a persistent vegetative state. She cannot speak. What she sees and hears is a mystery. Her fingers curl tightly into her palms. She has metal rods in her back and right leg to support her fragile bones. She must be carried or carted everywhere. She has been fed through a tube three times a day for the past seventeen years. She is given medication to control her seizures and relax her ever-tense muscles. Her care has cost many thousands of dollars, a financial burden that has been carried in large part by insurance, Medicaid, and the generosity of those physicians who have attended her.

Valerie's prognosis is not hopeful. She will never gain more awareness of herself nor the world around her. When she was two months old and well enough to be released from the hospital, her mother and I were invited to an exit conference with the attending neurologist. He was blunt, and his words will forever be etched into my memory. "Everything from the ears up is gone," he said. "I'd recommend that you place her into an institution." We took her home instead.

Caring for Valerie has never been easy, but it has become routine. A typical day for her begins at 5:30 am. Her mother wakes her up, dresses her, feeds her and places her into her wheelchair. A bus picks her up and takes her to the local high school where she joins five other students in the special needs classroom. She is given occupational and physical therapy and is taken on occasional field trips. She receives abundant attention from teachers, aides and her fellow classmates. One boy even calls Valerie his girlfriend.

When she comes home we place her on a cot in the family room. Sometimes, when the weather is nice, we take her for a walk or just let her sit in the warm sunshine. About 8 pm, after she is fed and diapered we carry her to bed.

Besides the excellent educational services that Valerie receives, we are also grateful for other services for which she qualifies through the Medicaid Waiver program. A therapist visits her once a week in our home, and a caseworker tracks her well-being quarterly. She also receives several hours a month of respite care. This has given us welcome breaks from the intense physical and emotional stress of caring for her, and afforded our family opportunities to take much-needed vacations. This program also pays for her food and diapers. Since she turned 18, Valerie has also received Supplemental Social Security Income. These funds supplement our household income to provide for her clothing, transportation, medical, and assistive device needs.

Valerie will ever remain a life in need of total care. She will never hold a job. She will never vote in an election. She will never exercise her freedoms of speech, assembly or religion. She will never make a positive contribution to society. Of what value, then, is her life? For what purpose, then, should her life be sustained?

I am not a philosopher, theologian, physician or judge. I claim no special knowledge. I am a father. I have a simple faith. I have had to wrestle with these questions for many years. I know that my answers will find little favor with current polls and pundits. The merits of Valerie's life cannot be determined by how she can think or what she can do. Her worth cannot be evaluated by how much she is wanted by me or anyone else. Her value cannot be judged by the ones who may see her as less than fully human, but only by the One who sees her as made in His image and likeness. And it is only through the eyes of faith that I have come to see her in that way, too.

I have come to realize that her life, as wounded and powerless as it is, is not a burden to bear but a gift to cherish. It is not something over which to exert control but to assume stewardship. I began to see that her long-suffering has a purpose. She has taught me how to love unconditionally, how to give sacrificially, and how to serve humbly. She has made me a better husband and father. I will forever be grateful to the many doctors, nurses, social workers, therapists, teachers, clergy, family and friends who have also seen the value of her life.

Many have concurred with the sentiment that they would not want to live "like that". Many have asserted that Terri Schiavo had a right to die. It is frightening to me that the value of Ms. Schiavo's life, as measured by the scales of our justice system, did not merit even food and water. I fervently hope that such scales will never be used to assess the value of my daughter's life, and dreadfully anticipate the day when her right to die may become her duty to die.

I appeal to this subcommittee to promote policies and legislation that both protects the lives of incapacitated citizens like my daughter and encourages and enables their families to provide for their needs. Thank-you again for the opportunity to testify on these matters, and may you be guided by wisdom and compassion as you consider your recommendations.